

Being a Woman Is 100% Significant to My Experiences of Attention Deficit Hyperactivity Disorder and Autism: Exploring the Gendered Implications of an Adulthood Combined Autism and Attention Deficit Hyperactivity Disorder Diagnosis

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Abstract

This article provides original insight into women's experiences of adulthood diagnoses of attention deficit hyperactivity disorder (ADHD) and autism. Research exploring experiences of adulthood diagnoses of these conditions is emerging. Yet, there is no research about the gendered experiences of an adulthood combined ADHD and autism (AuDHD) diagnosis. This article addresses this gap through interpretative phenomenological analysis of email interviews with six late-diagnosed AuDHD women revealing the complex interplay between late diagnosis, being a woman, and combined diagnoses of ADHD and autism. It underscores how gender norms and stereotypes contribute to the oversight and dismissal of women's neurodivergence. Interpretative phenomenological analysis reveals the inextricability of femininity and neurotypicality, the gendered burden, discomfort, and adverse consequences of masking, along with the adverse outcomes of insufficient masking. Being an undiagnosed AuDHD woman is a confusing and traumatising experience with profound and enduring repercussions. The impact of female hormones exacerbated participants' struggles with (peri)menopause often being a catalyst for seeking diagnosis after decades of trauma. The epistemic injustice of not knowing they were neurodivergent compounded this trauma. Diagnosis enabled participants to overcome epistemic injustice and moved them into a feminist standpoint from which they challenge gendered inequalities relating to neurodiversity. This article aims to increase understanding and representation of late-diagnosed AuDHD women's lived experiences. The findings advocate for trauma-informed pre- and post-diagnosis support which addresses the gendered dimension of women's experiences of being missed and dismissed as neurodivergent. There needs to be better clinical and public understanding of how AuDHD presents in women to prevent epistemic injustice.

Keywords

attention deficit hyperactivity disorder; autism; AuDHD; gender; adulthood diagnosis; feminism; epistemic injustice; standpoint theory; co-morbidity

Introduction and Background

Historically, attention deficit hyperactivity disorder (ADHD) and autism were thought to only affect male children (Vincenti et al., 2023). The absence of women from research has produced diagnostic criteria based on male presentations of the conditions, resulting in women's underdiagnosis (Driver & Chester, 2021; Peng & Watts, 2023). This is changing as more women become aware of these conditions and are diagnosed (Chester, 2019).

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Nevertheless, women encounter significant challenges including lengthy waiting lists, a lack of support, sexist diagnostic criteria, and the burden of coping with misdiagnoses, poor mental health, and internalisation of negative perceptions about their character (Bargiela et al., 2016; Beck et al., 2020; Vincenti et al., 2023). Women's late diagnoses of autism and ADHD are a pressing public health issue with implications for healthcare, research, public awareness, and the (gendered) lived experiences of both conditions.

Research has begun to explore experiences of adulthood diagnoses of autism (Lilley et al., 2021; Kelly et al., 2022) and ADHD (Redshaw & McCormack, 2022). This emerging literature identifies the need for studies that explore the lived experiences of autistic and ADHD adults with the ethos of critical disability studies and advocacy organisations which centre the voices of disabled individuals (Autistic Self Advocacy Network, n.d.; den Houting et al., 2021; Milton, 2020).

Yet, no research presently considers women's experiences of combined diagnoses of ADHD and autism. This article addresses this gap by providing original insight into late-diagnosed autistic and ADHD (AuDHD) women's experiences to reveal the gendered implications of adulthood AuDHD diagnoses. Through interpretative phenomenological analysis (IPA) of email interviews with six late-diagnosed AuDHD women, it reveals the complex interplay between late diagnosis, being a woman, and the combined manifestation of ADHD and autism. This article makes a significant contribution to knowledge and understanding of women's experiences of both conditions, bringing the literature about gender, adulthood diagnoses of autism, and ADHD into conversation with each other. The original findings have significance for healthcare policy and practice, AuDHD women, and sociological understandings of neurodiversity.

Diagnostic Criteria: ADHD and Autism

ADHD and autism spectrum disorder (ASD) or autism spectrum condition (ASC) are defined by the fifth edition of the American Psychiatric Association's (APA) *Diagnostic and Statistical Manual of Mental Disorders* (DSM-V) as neurodevelopmental disorders that affect children and adults, manifesting during childhood (APA, 2013).

ADHD is characterised by persistent patterns of inattention, hyperactivity, and impulsivity that interfere with daily functioning. There are three subtypes: Predominantly Inattentive; Predominantly Hyperactive-Impulsive; Combined (APA, 2013). Autism is characterised by challenges in social interaction, communication, and restricted or repetitive behaviours (APA, 2013). It is a 'spectrum disorder' because individuals vary in their presentation. Autistic community definitions centre 'spiky profiles' of varying impairments (Murray, 2019) and sensory challenges (Leadbitter et al., 2021). It was not

possible to be diagnosed with autism without a learning disability before 1992 (Vincenti et al., 2023).

There are critiques of the diagnostic criteria including its cultural relativism, disconnect from lived experiences, and medicalised deficit-based definitions (Grønneberg et al., 2024; Jutel, 2009). The neurodiversity paradigm subverts this medicalised understanding by asserting that diversity is an inherent aspect of humanity (Milton, 2020). Individuals with neurological differences are 'neurodivergent', while the neuro-majority is 'neurotypical'. Neurodivergent individuals constitute a minority, encountering structural barriers in a world predominantly designed for and by neurotypicals (Milton, 2020). Participants sought diagnoses of ADHD and autism, suggesting their usefulness as explanatory concepts, in the absence of alternatives.

Since the removal of the DSM-V's prevention of a combined diagnosis in 2013, individuals have been diagnosed with co-occurring ADHD and autism. Studies show significant correlation between the two (Antshel & Russo, 2019; Panigiotidi et al., 2017), with 40%–70% of autistic people also having ADHD (Rong et al., 2021) and 20%–50% of those with ADHD being autistic (Hours et al., 2022; Rommelse et al., 2010). Despite this, there is a lack of research that explores the experience of a combined ADHD and autism diagnosis, which is a gap this article addresses.

Sex Bias, ADHD, and Autism

Women are diagnosed with ADHD later than men. Women are more likely to display internalised symptoms such as emotional dysregulation and inattentiveness (Quinn & Madhoo, 2014) and to mask their struggles (Waite, 2010). Therefore, Quinn (2005) calls ADHD the 'hidden disorder' in females. Recognising ADHD in women is complicated by the gendered prevalence of psychological comorbidities, especially depression and anxiety (Attoe & Climie, 2023). Gender roles exacerbate the impact of ADHD with delayed diagnosis causing a lifetime of struggles (Attoe & Climie, 2023). Likewise, male bias in autism's diagnostic criteria, a different presentation in females, and masking have resulted in women being undiagnosed (Brugha et al., 2016).

A Note on Language Use

Language preference is individual and evolving. Currently, I use 'autistic and ADHD woman' and 'AuDHD'. Although grammatically incorrect, this reflects community preferences for identity-first language that integrates both conditions (Kenny et al., 2016).

The following outlines the methodology used to explore women's experiences of adulthood ADHD and autism diagnoses. Then, analysis is provided of the interplay of late diagnosis, gender, and combined ADHD and autism diagnoses, highlighting how women's neurodivergence is

overlooked due to stereotypes and masking. The detrimental impacts of living undiagnosed are emphasised, underscoring the need for tailored trauma-informed support before and after diagnosis.

Methods

Approach

Interpretative phenomenological analysis (IPA) was used because it prioritises an in-depth exploration of subjective experiences to uncover nuanced meanings and how individuals make sense of their experiences (Smith et al., 2022). IPA is iterative and reflexive and emphasises the uniqueness of each participant's perspective. It is therefore suited to centring unheard voices and has been used successfully to research autistic experiences (Howard et al., 2019; MacLeod, 2019).

Originally, phenomenology was a philosophical method for studying consciousness and describing the essence of experiences. Heidegger developed phenomenology from description towards interpretation, adopting an intersubjective perspective that recognises the situated and interpretative nature of knowledge (Smith et al., 2022).

Building on Heidegger, Smith created IPA in the 1990s to understand experiences in the context of the person's relationship to the world and their attempts to make meaning. IPA is idiographic, focused on the particular in its depth of analysis, and interpretative, acknowledging the double hermeneutic process of the researcher attempting to make sense of participants' sense-making (Smith et al., 2022).

Although originally psychological, IPA's emphasis on the interaction between participants and their social and political contexts makes it suitable for sociological studies focused on developing in-depth understanding of a particular experience, in this case, the experience of being a late-diagnosed AuDHD woman.

Sampling

The study comprised a purposive sample of six participants, recruited through online calls via Twitter, Facebook, and mailing lists. Selection criteria included females in the United Kingdom who received both ADHD and autism diagnoses in adulthood. While the sample size is modest, the consensus in IPA suggests adequacy (Smith et al., 2022) as the aim was gathering rich, quality data rather than quantity, for in-depth analysis.

Participant Characteristics

Participants, aged 34 to 55, were all white. Two held PhDs, two were unemployed, and four were employed full time. Two identified as working class, four as middle class, two as bisexual, and four as heterosexual. Four were

single, two in relationships or married, and two had children. All received diagnoses 6 months to 3 years before the study. Five participants were diagnosed in the United Kingdom, and one was diagnosed while living abroad. Half of the participants were diagnosed by the National Health Service (NHS) and half were diagnosed privately, due to facing barriers accessing NHS healthcare.

Data Collection

Semi-structured email interviews were individually conducted, allowing participants to express their experiences freely. The interview guide, derived from the research question 'What is it like being a late-diagnosed autistic ADHD woman?', was co-produced with non-participant AuDHD women and underwent pilot testing. Questions were related to women's experiences of living with ADHD and autism, their diagnosis process, post-diagnosis experiences, and their identity. Participants chose to receive all questions at once or consecutively, with the researcher following up on points of interest which enabled flexible, inductive exploration of participants' experiences through tailored questioning.

As neurodivergents, participants appreciated the freedom of written communication, which offered time for reflection and removed social and speaking barriers. Email interviews have successfully been used with autistic participants and other marginalised groups (Ayling & Mewse, 2009; Benford & Standen, 2011). Transcripts varied in length from 11 to 135 pages. This variety of responses is one limitation of using email interviews, as well as the additional researcher time and follow-up required.

Data Analysis

IPA entails analysing one transcript at a time. First, I read the transcript multiple times, noting initial thoughts. Deep reading enables the participant to become the focus of analysis (Smith et al., 2022). Second, I made specific and detailed exploratory notes based on semantic content and language use (Smith et al., 2022) – for example, "Finding a gym class that works for me – suited to my ADHD brain" and "'my ADHD brain' – suggests it is separate to herself." Third, experiential statements were constructed which condensed exploratory notes to capture the meaning of participants' words and my interpretation (Smith et al., 2022). For example, "I knew deep down that I was autistic but needed external validation." Fourth, I mapped connections between experiential statements, clustering statements. These clusters became the participant's personal experiential themes (PETs) and were given a descriptive title. For example, "Life in all honesty has been a bit of a roller coaster." PETs are personal as they are focused on the individual case, experiential as they relate

directly to experience or sense-making, and themes as they reflect analytic concepts present across the transcript rather than specific statements (Smith et al., 2022).

Once this five-step process was completed for each transcript, group experiential themes (GETs) and sub-themes were developed by comparing PETs across cases. This article explores the GET *Being a woman is 100% significant to my experiences of ADHD and autism*.

Ethical Considerations

Ethical approval was obtained from Birmingham City University. Participants provided written informed consent to the researcher prior to participation. Pseudonyms are used to maintain anonymity. I created and shared a resource list about women, ADHD and autism at study completion, and a feminist ethic of care guided relationship building. I kept a reflexive journal throughout, which was important as an ‘insider researcher’ – a white autistic ADHD woman. I acknowledged the interaction between my and participants’ experiences but kept an open mind and focused on participants’ perspectives, whether they resonated with my own or not. As an ‘insider researcher’, the emotional toll was managed through intentional, slow scholarship.

Trustworthiness

Member-checking occurred within email interviews, and a reflexive journal ensured transparency (Denzin & Lincoln, 2005; Lincoln & Guba, 1985). Discussions with an uninvolved colleague validated interpretations. Quotations from participants are used to illustrate and support the identified subthemes, enhancing the authenticity of the findings (Lincoln & Guba, 1985; Smith et al., 2022).

Limitations

Potential limitations include the homogeneity of the all-white participants and the UK-centric focus. Future research should explore diverse experiences pre-diagnosis, include

self-diagnosed individuals, and broaden the scope beyond the United Kingdom.

Analysis

The following sections explore the gendered dimension of adulthood ADHD and autism diagnoses through discussion of the GET and subthemes identified in Table 1. In line with Smith et al.’s (2022) guidance, the titles reflect the shared meanings across narratives and are rooted in participants’ experiences. All participants said being a woman was significant, with three participants using the term ‘100%’ to convey the all-encompassing impact of gender on their experiences of being late-diagnosed AuDHD women.

Missed and Dismissed Because of Gendered Stereotypes

Because participants did not meet gendered stereotypes of autism and ADHD, they were missed (unrecognised and undiagnosed) by others and themselves. The stereotypical image of autism is “socially awkward men who struggle with social interaction or perhaps collect facts” (April). A lack of female representation prevented participants from recognising autism and ADHD, suggesting that there is a sex difference in the presentation of both.

I only really knew what was portrayed on the TV, especially about autism and I didn’t know much about what female traits were at all for either condition. (Margaret)

I didn’t really have any training in ADHD and I thought it was more the stereotype running around stuff and also stereotyped to boys. (April)

The above quotations demonstrate the central role media and public discourses play in constructing knowledge. Participants’ narratives reveal epistemic injustice (Fricker, 2007), specifically hermeneutical

Table 1. Group Experiential Theme and Subthemes.

Group Experiential Theme
Being a woman is 100% significant to my experiences of ADHD and autism.
Subthemes
Missed and dismissed because of gendered stereotypes
The invisibility cloak of neurotypical femininity
The invisibility cloak of neurotypical femininity is heavy, uncomfortable, and doesn’t always work
Not knowing I was autistic and ADHD was confusing and traumatising and has had lasting effects

injustice, where individuals lack access to knowledge they need for understanding themselves, with others having more power to interpret one's experiences than the experiencer does. April, a clinical psychologist, reinforces the systemic nature of hermeneutical injustice by highlighting the lack of knowledge about female presentations of ADHD and autism in mental health services.

[Females are] overlooked, definitions on males, different presentation still not officially defined as a 'separate' list for females which it should be.

April implicitly adopts a feminist perspective, drawing attention to the centring of the male experience within healthcare and how this is naturalised with women being 'overlooked' and forgotten.

Chloe proclaims the role that patriarchy and racism play in neurodivergent women and girls being missed and dismissed. Unfortunately, this study's sample was white and so analysis relating to race is not possible.

It's the pervasive institutional and societal sexism, duh! I hate that the majority of the published literature on "why aren't there as many autistic or ADHD girls as boys" tries to put it down to ANYTHING other than sexism/racism being utterly engrained in all of our social institutions and society in general. Far too many researchers pussy-foot around it rather than calling it what it is and doing anything about it! It drives me UP. THE. WALL!

Chloe's use of 'duh!' suggests that this is an obvious, accepted fact, yet it is at odds with popular scientific discourses. Chloe identifies systemic epistemic injustice and shows awareness of the political nature of hegemonic gendered discourses, with her suggestion that researchers fear challenging these.

Participants' narratives can be interpreted via standpoint theory which posits that individuals' personal knowledge has authority with marginalised individuals being in a unique 'outsider-within' position to recognise dominant patterns of behaviour and discourses that go unnoticed by the majority (Harding, 2004). Learning about AuDHD women's experiences and receiving a combined diagnosis enabled participants to challenge epistemic injustice through the development of counter-knowledge. With this, the participant moves into a feminist standpoint from which they can see and challenge gendered inequalities relating to neurodiversity.

Participants were further missed and dismissed because of gendered stereotypes of mental health, with women more likely to be diagnosed with mental health conditions. Amelia links the lack of knowledge about neurodiversity in women to the misdiagnosis, and subsequent labelling, of women, displaying a latent

awareness of the potential for such labels to produce stigma. She asserts a call to action.

I think there should be a lot more awareness of the combined conditions and feel women are being labelled bipolar or having personality disorders as enough isn't known about how these conditions present both individually or together in women. This needs to change.

Meredith and Juliette bolster this:

I was also frequently diagnosed with anxiety, depression, low mood and other related conditions over a 20+ year period, when realistically these were all related to AuDHD. (Meredith)

For years, I believed that I was bipolar but now believe that what I was experiencing was a combination of ADHD hyperactivity, autistic burnout, and antidepressant-induced hypomania. (Juliette)

The above quotations demonstrate how participants reframe their lives via a diagnostic lens, with life being divided into before and after their diagnosis. Diagnosis provides a language to make sense of their struggles, thus challenging the epistemic injustice they previously faced.

Notably, the combination of ADHD and autism contributed to women being missed and dismissed, as not only did they not fit gendered stereotypes but they also did not fit one or the other diagnostic criteria. As a combined diagnosis was not possible before 2013, not fitting neatly within one diagnostic box resulted in being undiagnosed. Participants explain how the experience and presentation of both can result in one masking the other.

The traits overlap at times, cancel each other out and at different periods in your life you may present as more autistic or the ADHD may take the lead. (Amelia)

However, a diagnosis is not an automatic ticket to recognition and acceptance for women. The enduring influence of gendered stereotypes resulted in others dismissing their diagnoses. There is a need for better clinical and public understanding of how the two conditions interact and present in women to prevent epistemic injustice and women's neurodivergence being missed and dismissed.

The Invisibility Cloak of Neurotypical Femininity

This subtheme explores the gendered dimension and consequences of participants' attempts to mask – adopting behaviour to be perceived as neurotypical. There is a

gendered dimension as women attempted to not only fit in with the neurotypical majority but also adequately perform femininity, to fit in as a woman.

The subtheme's title alludes to a magical item in mythological tales that enables the wearer to pass unseen. Participants made references to fantasy throughout their narratives, including the Wizard of Oz and Harry Potter, communicating their feelings and experiences via allegory. Such references conveyed a sense of escapism to a familiar, simpler world and harnessed popular imagery to articulate their experiences in a way that might be understood by outsiders.

Despite internally feeling different, participants did not want to externally appear different and so adopted the invisibility cloak of neurotypical femininity. Gendered experiences of masking combined with gendered stereotypes of autism and ADHD to render AuDHD women and girls invisible:

I learnt to be social because that was important especially to a girl. Essential to trying to 'fit in'. I was very clever and related better to adults, teachers liked me for this. But also I stuck to the rules so wouldn't always fit in and be liked by others from a young age. Left me feeling there was something wrong with me yet no-one ever considered autism – because I wasn't stereotypical of symptoms which are male based. (April)

As April appeared externally to perform well and did not pose a problem to others, her internal experience was ignored. This neglect of internalised presentations of ADHD and autism reflects the diagnostic criteria's emphasis on externalised behaviours that pose problems to others or that contradict social norms.

Women's struggles 'behind the scenes' were hidden by their academic and gendered performances:

I was quiet, studious, (apparently) hard-working, was a 'pleasure to have in class', etc. This meant my teachers never saw the struggles I had with procrastinating on everything, nor the copious tears that came with said chronic procrastination. That is, they completely missed my executive dysfunction and spiky cognitive profile that should have pointed to ADHD. (Chloe)

Chloe reframes her childhood experience via a diagnostic lens that now recognises her ADHD. She uses terminology that is a combination of shared language in neurodiverse communities ('spiky cognitive profile') and medicalised language ('executive dysfunction'). This serves to legitimise her experiences while positioning herself as an authoritative voice, an expert by experience.

Similarly, Juliette explains how her external appearance at work masked her internal struggles:

I think that people often perceive me as being ok even when I'm not. When I worked [...] there were times when I was suffering from terrible stress, sensory overload, and daily suicidal ideation for weeks at a time. But neither my boss nor my colleagues picked up that anything was wrong. Nobody asked me if I was ok. This has been a recurring theme in my life. So in that sense I feel burdened by having to make those around me aware that I'm not coping, which can be challenging when your outward presentation and behaviour do not reflect your internal experiences. (Juliette)

Because women's struggles are experienced more internally and masked more heavily, the onus is placed on women to articulate their struggles and seek help, which creates further barriers.

I found it difficult to advocate for myself; it just feels as if you're complaining all the time about the smallest things. (Juliette)

There is perhaps a gendered element to Juliette's reticence to seek support, given that girls are socialised to be passive and uncomplaining, with assertiveness often misinterpreted as aggression.

Participants put on the invisibility cloak of neurotypical femininity to fit in. However, the cloak made their neurodivergence invisible, meaning their internal struggles were missed.

The Invisibility Cloak of Neurotypical Femininity Is Heavy, Uncomfortable, and Doesn't Always Work

The gendered masking burden weighed heavy on participants. For Juliette, attempts to perform femininity caused discomfort that was directly related to her sensory challenges as an autistic woman, suggesting that gendered expectations are also implicitly neurotypical and ableist.

My sensory discomfort has been increased by wearing bras and high heels (these days, I try not to wear either!) [...] Throughout my life, I have often tried to mimic the appearance of other women, including their style of dress. So wearing heels or nice outfits was very much part of my attempt to fit in. But the physical discomfort was just too much. My feet would often rub and I would get blisters. So I stopped wearing heels a few years ago other than on special occasions, such as a special dinner. (Juliette)

This quotation shows the post-diagnosis progress Juliette has made in recognising and meeting her needs – she no longer dresses in a way that triggers sensory discomfort to pass as neurotypically feminine. However, the use of the word 'try' suggests that challenging ingrained gender

norms requires effort and that while wearing heels and dresses might cause sensory discomfort, not doing so causes social discomfort.

Juliette also reveals the insidious nature of gendered discourses, suggesting she would have to ‘make an effort’ if she were in public with others.

Now that I’m staying with my mum and rarely see anyone else, I try to dress as comfortably as possible, which means flat shoes, no bra, and soft, loose clothing. I will make more of an effort to be presentable if I meet up with someone though.

Juliette exposes underlying anxieties about being perceived as unpresentable and not having ‘made an effort’, with the implication being that women must put work into their appearance which must conform to gendered expectations. Gendered norms place Juliette between a rock and a hard place – both conforming and resisting require effort and cause discomfort.

The pressure Juliette feels to perform neurotypical femininity potentially reflects a deep-seated awareness of the consequences of ‘failing’ in this performance. Unsuccessful attempts at performing femininity resulted in women being perceived as (and bullied for being) doubly different – because of their neurodivergence and failure to achieve idealised femininity:

As a girl, I was bullied at school not just for being ‘odd’ but also for being perceived as ugly by boys, so I think that my sense of alienation and difference was increased by these gendered experiences. (Juliette)

Being bad at performing the femininity and maintaining the female social relationships expected of me was a key factor in the years of bullying I endured, and being bad at being feminine and female relationships was a direct consequence of me being undiagnosed autistic. (Chloe)

Like Juliette, Chloe’s experiences of gendered masking are related to her autistic experience. Her comments associate being bad at performing femininity with being autistic implying that the two cannot co-exist. While ‘being bad at’ infers a negative self-perception, Chloe’s narrative proudly situates herself as a rebel who has defiantly resisted gender roles and norms.

Meredith attests to the negative consequences of wearing the invisibility cloak of neurotypical femininity and its incompatibility with autism.

My self-esteem and personal boundaries have been severely affected by expectations/perceived expectations of what a girl/woman ‘should be’. I have been sexually assaulted on several occasions because of, what I now can see, is my inability to read a situation or to know that something is just ‘not okay’.

Being a woman is inherently risky in a patriarchal society that enables violence against women. Being an autistic woman adds another layer of risk as tacit gendered knowledge about keeping oneself safe is harder to learn. Similar to accusations of blame and interrogations of women’s character and behaviour (e.g., what women were wearing and whether they had drunk alcohol) that place responsibility on women to avoid sexual assault (thereby removing responsibility from the perpetrator), Meredith’s experience sheds light on the existence of implicit gendered knowledge that girls and women are socialised into. Again, we can apply feminist standpoint theory with Meredith occupying an outsider-within position that exposes the hidden workings of the patriarchy.

Chloe corroborates Meredith’s experience, drawing attention to the enhanced vulnerability for sexual assault associated with being undiagnosed autistic.

Being ‘officially’ autistic, and therefore struggling socially far beyond what most normal people do, meant that I wasn’t actually a failure of a person and wasn’t actually to blame for the years of bullying I endured, or the string of sexual assaults and worse that I suffered. That what it was instead was that, as an undiagnosed autistic girl, I was a vulnerable target because I was naïve and poor at reading social cues, and at noticing social danger signs/red flags. That a string of bad people taking advantage of my vulnerability over the years was actually not my fault in any way. (Chloe)

Being recognised as ‘officially’ autistic legitimises Chloe’s experience and marks her apart from ‘normal [neurotypical] people’. Chloe subverts normality in her narrative with ‘weird’ having positive connotations as a signal of neurodiversity. The quotation marks around ‘officially’ hold space for doubting the authority of medical professionals to hail a person as autistic while also recognising the significance of this marker of legitimacy for Chloe and others. Chloe was always autistic; however, the diagnosis provides her with permission to claim the label and reframe her life. Her repetition of not being to blame could be read as a defiant assertion or as an attempt to convince the researcher and herself, signifying lingering traces of her previous feelings of self-blame.

Other negative consequences of masking are uncovered by participants who illuminate how maladaptive coping mechanisms that enabled them to mask, such as drinking alcohol, heightened their vulnerability:

In my teens I began to drink, it helped me be social and feel ‘normal’ but in reality I ended up in many unsafe situations because of it. (Amelia)

Amelia used alcohol to access a neurotypical world through changing her external behaviour to ‘be social’ and to alter her internal perceptions about herself, to feel ‘normal’ (neurotypical) by masking her difference, and by

implication, her abnormality (neurodiversity). Amelia's use of quotation marks signifies a post-diagnostic shift in her understanding of normal. The phrasing "ended up in many unsafe situations" relinquishes responsibility – it is not something she did to herself, or that was caused by being autistic, but instead something that happened to her.

However, given the negative messaging and accumulative trauma participants experienced, removing blame from themselves and their neurodiversity (as Chloe and Amelia do above) was difficult to fully achieve. When discussing the negative impacts of being undiagnosed, Amelia appears to place responsibility on herself and her ADHD: "doing things in impulse [an ADHD characteristic], drinking when younger and putting myself in dangerous situations resulting in trauma, the list goes on" This could reflect a temporal shift with Amelia thinking about previous experiences and imagining herself back in that moment when she held the belief that it was her fault. It could also signal the ongoing project of recovering self and narrative. The back and forth in participants' narratives suggests that this requires continuous effort and unveils the lasting effects of accumulative trauma.

Participants' narratives reveal the inextricability of femininity and neurotypicality, the gendered burden and discomfort of masking, and the negative consequences of masking and of masking insufficiently. The invisible cloak of neurotypical femininity did not always work and instead made participants' difference more visible while rendering their vulnerability invisible.

Not Knowing I Was Autistic and ADHD Was Confusing and Traumatising and Has Had Lasting Effects

Being an undiagnosed girl and woman is a confusing and traumatising experience. Participants experienced gender-based violence, abusive relationships, interpersonal challenges, academic and employment barriers, poor mental health, "the list goes on" (Amelia). The previous sections have explored some of the trauma resulting from being missed and dismissed as neurodivergent. The epistemic injustice of not knowing they were neurodivergent compounded this trauma.

All participants had experienced unexplained psychological and physical symptoms that they now attribute to the accumulative impact of trauma from undiagnosed neurodivergence:

The stress was making me ill. My hair was thinning and I was getting chest pains. I was taken for an x-ray and ECG for the chest pain but nothing was physically wrong. (Juliette)

All through life I went through periods of not coping, I was physically unwell at times, but there was never a cause, I had anxiety from childhood, but never realised what it was at that time. (Amelia)

The impact of female hormones exacerbated the struggles faced by participants with (peri)menopause often being a catalyst for seeking a diagnosis after decades of unexplained struggles and trauma.

I feel certain that my female hormonal cycle has exacerbated my emotional dysregulation, making my conditions even more difficult to manage. (Juliette)

Perimenopause exacerbated the symptoms and increased my anxiety and sadness, gave me the worst brain fog. (Margaret)

There are a lot of peri/menopausal women hitting a wall at this time and only then realising neurodivergence because suddenly things can be too much and [they] realise they've masked [their] entire lives ... there is a clear link to late diagnosis of AuDHD of women who mask and struggle through decades and then the wheels fall off (April)

But it was when my grandson was born 11 years ago and I had also started my perimenopause journey, that things began to come to a head. (Amelia)

Amelia's crisis point was created by a combination of perimenopause and taking on caring responsibilities for her grandson, being "thrust into the mothering role again," illuminating the additional gendered challenges of being an undiagnosed neurodivergent woman. The epistemic injustice of not having the knowledge that they were AuDHD prevented women from preparing for (peri) menopause and understanding the additional struggles they faced.

Participants knew that they were 'different' from a young age: "I have always felt different, a bit of an outsider" (Meredith). However, they did not have an explanation for their difference which led to the internalisation of negative judgements about themselves, damaging their self-esteem and self-concept.

Before diagnosis I felt I was a failure in many aspects of my life. (Amelia)

After receiving my diagnosis confirmation I was further relieved (as there was always the fear that I was wrong and I was just 'a bit faulty'). (Meredith)

I thought that I was lazy but recognised that I barely sat down and I couldn't rest. (Margaret)

I internalised a sense that I needed to become more 'resilient' and 'grow a thicker skin'. This is what people told me I

needed to do. But, of course, I was never able to and felt deficient because of this. (Juliette)

Attempts to reauthor their lives and make sense of their past experiences in light of their diagnoses were challenging having spent so long holding a negative self-concept and seeking solutions.

I've also had periods where I've felt trapped, because for so much of my adult life I've tried all different ways to 'fix' myself (to no avail, of course!), and knowing that there isn't a fix can be hard to take. (Meredith)

The enduring consequences of living a life undiagnosed are foregrounded by participants reflecting on what could have been, had they received an earlier diagnosis.

Going through the system or struggling on your own for so many years while not knowing why your mental health is so awful can erode your confidence and damage your sense of self so profoundly. Over the years, I have felt so 'mad' and unstable. Sometimes I wonder whether an earlier diagnosis might have helped me to understand my brain better and develop a more robust, resilient, stable sense of self [...]. I think that I would be a very different person today had I been diagnosed as a child or younger adult. (Juliette)

I've gone through a period of grieving for the life I could have had, for the lonely child that I was, and for poor decisions I've made. (Meredith)

Juliette and Meredith show the lasting impact of negative messages, with Juliette internalising the value placed by others on resilience despite challenging it earlier and Meredith still blaming herself for "the poor decisions I've made."

Participants substantiate the negative enduring impacts of living a life undiagnosed and misdiagnosed. Yet, post-diagnosis support is lacking, leaving women to process and navigate life-changing information by themselves.

This is all new, I have no support as I don't believe there is any. (Amelia)

Honestly, I think that I need a lot more support than I currently have. I am unemployed, mentally fragile and socially isolated. (Juliette)

Some participants felt therapy was invaluable at supporting them to reclaim their lives and sense of identity post-diagnosis. However, cost barriers prevented them from adequately accessing this. Rather than an end, diagnosis is the beginning of sense-making about living

with ADHD and autism, which can be confusing and contradictory.

Discussion

Due to male bias in diagnostic criteria and assumptions that ADHD and autism occurred exclusively in boys, women have only recently begun to be diagnosed. We are in the infancy of research exploring women's adulthood diagnoses of autism and ADHD. However, there is no research that considers late-diagnosed women's experiences of both. This article is the first to explore the gendered implications of late diagnoses of AuDHD, revealing the complex interplay of adulthood diagnosis, being a woman, and a combined diagnosis of ADHD and autism.

Findings have revealed how gendered stereotypes resulted in women's neurodivergence being missed and dismissed by healthcare professionals, people in their lives, and themselves. The male bias of diagnostic criteria results in clinicians not recognising female presentations. Women are more likely to present with inattentive ADHD and experience more internalised symptoms, such as racing thoughts, while the diagnostic criteria is based on externalised symptoms of hyperactivity, meaning that ADHD in girls is missed (Vincenti et al., 2023). As clinicians are more familiar with identifying autism in boys, girls' presentation is more likely to go under the radar (Fletcher-Watson & Happé, 2019).

Research suggests the need for healthcare professionals to have an understanding of the different sex presentations of autism and for diagnostic criteria to be developed that reflect a 'female phenotype' of autism (Hull et al., 2020). It has been suggested that the threshold for women receiving a diagnosis of ADHD should be lower than the DSM-V currently affords (Young et al., 2020). Accessing an accurate and timely diagnosis is key to accessing support, accommodations, and legal rights, as well as for making sense of one's life, experiences, and identity.

Gendered stereotypes influence public perceptions resulting in women's diagnoses being dismissed for not fitting the images people have of autism and ADHD. Men often play fictional autistic characters, making it harder for the public to envisage autistic women (Murray, 2012). Therefore, "stereotypical autistic traits, and their discursive representations have been culturally coded as masculine rather than feminine" (Davidson, 2008, p. 660).

Gendered stereotypes about women being emotional and more susceptible to mental health conditions led to participants' neurodivergence being missed and dismissed as mental health conditions. Some participants felt they were misdiagnosed with mental health conditions, with medication having dangerous impacts, and others were

appropriately diagnosed with mental health conditions but felt that the root cause of these – their neurodivergence – was not recognised.

Although mental health conditions might be secondary to ADHD, they are more likely to be diagnosed as primary disorders (Young et al., 2020). At the same time, females with ADHD are more likely to develop depression and anxiety than males (Vincenti et al., 2023). Women interviewed in Holthe and Langvik's (2017) study had chronic anxiety and depression but asserted that these conditions were precipitated by living with ADHD. Struggles to maintain routines produced feelings of shame and a negative self-concept which resulted in depression and anxiety. This finding is significant for AuDHD women, with a need for structure and routine being characteristic of autism. Thus, the tension between needing routine and being unable to maintain one might exacerbate mental health effects, highlighting the complex and compounding experience of living with both ADHD and autism.

The internalisation of negative messages has lasting impacts on late-diagnosed women as they strive to re-author their lives and identities in a way that challenges previously held beliefs about being a 'bad' or 'broken' person (Stagg & Belcher, 2019). Gendered norms make it more likely for girls to receive negative messages related to their unrecognised ADHD as hyperactivity is more socially acceptable for boys (Young et al., 2020). In late-diagnosed autistic women, a lack of explanation for their difficulties resulted in women blaming themselves (Stagg & Belcher, 2019).

The implications are serious with self-harm present in 66% of ADHD females compared to 24.4% of comparison females (Owens et al., 2017) and suicidal behaviour being more prevalent in ADHD women than men (Vincenti et al., 2023). Treatment for ADHD therefore needs to include psychological interventions that help women to unpack how ADHD has become embedded in their self-concepts (Young et al., 2020).

Indeed, research shows (Fleischmann & Fleischmann, 2012; Leedham et al., 2019) that reauthoring is vital for developing a positive neurodivergent identity. Leedham et al. (2019) suggest that this can be achieved via autistic peer-led support. However, this raises questions about what the most useful post-diagnosis support is for AuDHD women. It is important that stigmatisation and isolation are not inadvertently generated by well-intentioned post-diagnosis initiatives. Therefore, the distinct experience of being AuDHD needs to be considered, alongside how it interacts with receiving an adulthood diagnosis and being a woman, as a triad of three closely connecting and mutually influencing aspects.

Another key contributing factor to women's neurodivergence being missed was masking, also referred to as

'camouflaging' – emulating neurotypical behaviours and/or hiding neurodivergent behaviours to be socially perceived as 'normal'. ADHD experts noted how girls with ADHD engage in more effective masking behaviours than boys, making their ADHD less likely to be diagnosed (Young et al., 2020). Late-diagnosed autistic women described learning social behaviours from other women and repressing autistic behaviours (Leedham et al., 2019). However, the lack of authenticity inherent in masking is particularly damaging to autistic women's self-esteem (Murray, 2020).

The ability to mask is positively correlated with intelligence (Fusar-Poli et al., 2022). Finch et al. (2022) found that autistic individuals' academic ability was prioritised over challenges they experienced, resulting in autism being unrecognised for men and women. Moreover, studies have shown that autistic individuals with an IQ of 70 and above have a higher rate of comorbid ADHD than autistic individuals with learning disabilities (Witwer & Lecavalier, 2010). Therefore, AuDHDers are more likely to measure with higher intelligence which provides skills for masking effectively, resulting in an increased likelihood of being unrecognised. Further research needs to explore the sex differences between academic performance, AuDHD, and diagnosis.

There was an additional gendered element to masking with women trying and struggling to fit gender roles and norms about what a girl should be and look like. Butler (2006) argues that gender is a performance informed by patriarchal expectations of women as feminine, passive, caring, and communicative. In order to be acceptable, women must adequately perform gender. This article has revealed how AuDHD women felt pressure to achieve this performance but often fell short, resulting in bullying from others and lowered self-esteem. Research about ADHD shows how failure to meet societal expectations about acceptable behaviour for women, for example, by engaging in casual sex, resulted in shame that prevented women from seeking sexually transmitted diseases tests, with potential negative impacts on their health (Young et al., 2020). Therefore, challenging gender norms and roles more widely has wide-reaching effects for AuDHD women.

This article reveals the additional masking burden created by gender roles. Research shows that mothers with ADHD struggle to cope with additional pressures combined with societal expectations of 'good mothering', which results in shame, negative self-concept, low self-esteem, and mental health conditions (Vincenti et al., 2023). Research about autistic mothers of autistic children has revealed the double-edged sword of masking as a protective activity that produces additional strain (Sanchez, 2023). Autistic and ADHD women are more likely to have neurodivergent children which can bring

additional parenting challenges and requirements to navigate myriad systems to receive support for their children (Sanchez, 2023). At the same time, autistic women who do not fulfil traditional gender roles of a mother or carer are stigmatised (Bargiela et al., 2016).

Women's struggles were exacerbated by female hormones, with (peri)menopause often being a catalyst for seeking a diagnosis. Research suggests that there is a higher prevalence of premenstrual dysphoric disorder (a severe form of premenstrual syndrome that causes emotional and physical symptoms during the 2 weeks before menstruation) and post-partum depression in ADHD women (Dorani et al., 2021). ADHD symptoms might be exacerbated by hormonal fluctuations during menopausal years and stages of the menstrual cycle (Quinn, 2005; Young et al., 2020), requiring dosage increases of medication (Dorani et al., 2021). Camara et al. (2021) suggest that evaluation of female hormones should be part of a holistic treatment plan for women with ADHD. However, very little research in this area exists. Autistic women experience additional sensory challenges during menstruation, but again, research is limited. Future research should explore the interaction between a combined diagnosis of both ADHD and autism and female hormones and menstruation.

Being undiagnosed resulted in a lifetime of traumatic experiences, reinforcing literature about late-diagnosed autistic adults (Bargiela et al., 2016). Women were particularly vulnerable to gender-based violence and sexual assault. Research shows that ADHD women had 1.85 greater odds of being raped than women without ADHD (Snyder, 2015). Fuller-Thomson et al. (2016) determined that ADHD females had a significantly higher likelihood of experiencing childhood sexual abuse than non-ADHD females (35.8% vs. 10.9%). Inattentiveness contributes to an inability to perceive danger cues (Wallin et al., 2022). Likewise, Bargiela et al.'s (2016) research participants reflected on how being autistic contributed to an inability to sense danger, read other people's intentions, and cope with dangerous situations. Significantly, autistic female participants felt that an earlier diagnosis would have helped them to avoid some of the abuse they had faced. Being both autistic and ADHD potentially heightens the risk of women being vulnerable to abuse and sexual assault. Earlier identification of both is pressing.

This article advocates for adequate post-diagnostic support that takes into account the complex traumatic lives of women and the gendered implications of their experiences. Support was found to be entirely lacking or behind costly barriers. Research affirms this gap in support for late-diagnosed autistic and ADHD women. Morgan (2023) noted that psychological and mental health support was absent for almost all participants post-ADHD diagnosis. Moreover, participants were unsure

who to seek support from in the absence of ADHD specialist support and having been discharged from services, often left with only medication but no review or additional support (Morgan, 2023). This is especially problematic given the need to adjust medication around menstrual cycles. Tailored support is required that takes account of the distinct experience of having a combined diagnosis of autism and ADHD.

The findings of this article reinforce research on both autistic and ADHD women's adulthood experiences. Women with a late diagnosis of both are therefore at risk of compounded negative impacts. This is complicated further by the complex interplay between ADHD and autism as a lived experience, which can feel confusing and contradictory, although there is insufficient space to explore this. Pre- and post-diagnosis support needs to not only consider gendered implications but also ensure that it is tailored to women with both ADHD and autism.

While in-depth IPA has the benefits of providing rich data and analysis that illuminates individuals' lived experiences of phenomena, it is limited to a smaller sample. Future research in this area should explore these findings on a larger scale, not to aim for generalisability, which is not fitting with qualitative research, but to capture the diversity of late-diagnosed AuDHD women's experiences. Future research should also consider intersections, especially race and class, which have been shown to impact diagnoses but which, unfortunately, were absent in this study. To ascertain gendered implications of experiences, it would be useful to compare women's experiences to men's – for example, do late-diagnosed males also experience pressures to perform masculinity? However, this should not be at the expense of research that centres women's voices.

Conclusion

ADHD and autism in girls and women have been missed and dismissed due to a combination of male bias in diagnostic criteria, differing presentations of conditions, and women masking their struggles. This has resulted in a generation of undiagnosed women who are now seeking diagnoses and explanations of the lifelong struggles they have endured. This article has demonstrated the gendered dimension of women's neurodivergence being missed and dismissed and the enduring negative consequences of this oversight. It has shown the complex interaction between adulthood diagnosis, being a woman, and a combined diagnosis of both ADHD and autism. It has argued that being missed and dismissed as neurodivergent constituted epistemic injustice because participants lacked the knowledge required to understand themselves. Diagnosis enabled them to overcome this injustice and moved women into a feminist standpoint from which they

challenge gendered inequalities relating to neurodiversity. This is the first article to consider late-diagnosed women's experiences of both ADHD and autism and to bring together literature about gender and adulthood diagnoses of both. It is hoped that providing this insight prompts further exploration of women's lived experiences and contributes to developing understanding, centred on the voices of women who have been silenced for too long.

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Ethical Statement

Ethical Approval

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